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# PEDSnet: a National Pediatric Learning Health System

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**ABSTRACT**

A learning health system (LHS) integrates research done in routine care settings, structured data capture during every encounter, and quality improvement processes to rapidly implement advances in new knowledge, all with active and meaningful patient participation. While disease-specific pediatric LHSs have shown tremendous impact on improved clinical outcomes, a national digital architecture to rapidly implement LHSs across multiple pediatric conditions does not exist. PEDSnet is a clinical data research network that provides the infrastructure to support a national pediatric LHS. A consortium consisting of PEDSnet, which includes eight academic medical centers, two existing disease-specific pediatric networks, and two national data partners form the initial partners in the National Pediatric Learning Health System (NPLHS). PEDSnet is implementing a flexible dual data architecture that incorporates two widely used data models and national terminology standards to support multi-institutional data integration, cohort discovery, and advanced analytics that enable rapid learning.

**BACKGROUND**

Most pediatric chronic conditions are rare diseases, requiring multi-institutional research networks to conduct research and learn how variations in clinical practice affect pediatric health outcomes.<sup>1–3</sup> A learning health system (LHS) integrates clinical studies done in routine care settings, leverages structured data capture at every encounter, and incorporates quality improvement methods to implement advances in new knowledge and care delivery, with active and meaningful patient participation.<sup>4–8</sup> While disease-specific examples of pediatric LHSs have shown tremendous improvement in clinical outcomes,<sup>9–11</sup> a national digital architecture to support the rapid implementation of LHSs across multiple pediatric conditions does not exist.<sup>12 13</sup>

PEDSnet is a clinical data research network (CDRN) that forms the digital infrastructure to support a national pediatric LHS. The PEDSnet CDRN is a consortium of eight children's hospitals, two existing patient-centered disease-specific pediatric networks addressing inflammatory bowel disease and complex congenital heart disease, a newly formed pediatric obesity network, and two national data partners. Together they form the initial components of the National Pediatric Learning Health System (NPLHS). The NPLHS will establish the data sharing environment to enable a community of patients and clinicians, interacting at the point of

care, to generate data that can be repurposed for research and quality improvement and to support continuous monitoring of outcomes that identify specific management practices as targets for comparative effectiveness research (CER). This brief report describes the PEDSnet CDRN digital infrastructure.

The PEDSnet CDRN is one of 11 CDRNs funded by the Patient Centered Outcomes Research Institute (PCORI) as part of the newly established PCORnet, a national patient-centered clinical research network for conducting clinical effectiveness research (see <http://www.pcor.net.org>).<sup>14</sup> PEDSnet consists of eight academic pediatric health centers: Children's Hospital of Philadelphia (CHOP), Cincinnati Children's Hospital Medical Center (CCHMC), Children's Hospital Colorado, Nemours Children's Health System, Nationwide Children's Hospital, St. Louis Children's Hospital, Seattle Children's Hospital, and Boston Children's Hospital. With regional catchment areas extending across 22 states, and a national and international specialty referral base, PEDSnet hospitals provide care for 2.1 million patients, or 2.8% of all children in the USA, from diverse demographic, geographic, and socioeconomic backgrounds (table 1). Additional participants include the ImproveCareNow (ICN) Inflammatory Bowel Disease Network,<sup>9</sup> the National Pediatric Cardiology Quality Improvement Collaborative (NPCQIC) which focuses on complex congenital heart disease,<sup>15</sup> and a newly formed Healthy Weight obesity prevention network. Partnerships with Express Scripts, a national pharmacy benefits management company, and IMS Health, a data aggregator of multi-payer administrative databases, extends the reach of NPLHS beyond the core PEDSnet CDRN institutions.

**THE PEDSnet CDRN DIGITAL INFRASTRUCTURE**

PEDSnet institutions use a variety of clinical systems from multiple vendors, including internal clinical registries (table 2). Differences in implementation and local documentation practices prevent institutions from sharing data, even among institutions that have installed the same vendor product.

**Interoperable dual common data models and environments**

The informatics teams in PEDSnet institutions have substantial expertise in two open-source data-sharing platforms—i2b2, developed by Harvard University,<sup>16</sup> and OMOP, created by the Observational Medical Outcomes Partnership.<sup>17</sup>

**Table 1** PEDSnet overview

	No. patients (%)
Total number of patients	2 171 000 (100%)
Age	
0–2 years (up to 23 months)	391 000 (18%)
2–5 years (24–59 months)	412 000 (19%)
5–11 years (60–43 months)	673 000 (31%)
12–17 years (144–215 months)	499 000 (23%)
18–24 years (216–287 months)	109 000 (5%)
25+ years (288 months+)	87 000 (4%)
Gender	
Female	1 042 000 (48%)
Male	1 129 000 (52%)
Race/ethnicity	
Asian	43 000 (2%)
Black or African American	391 000 (18%)
Hispanic or Latino ethnicity	174 000 (8%)
White	1 216 000 (56%)
Other/unknown	499 000 (23%)
Academic health center	
Boston Children's Hospital	235 000 (11%)
Children's Hospital of Philadelphia	435 000 (20%)
Cincinnati Children's Hospital Medical Center	231 000 (11%)
Children's Hospital Colorado	185 000 (9%)
Nationwide Children's Hospital	304 000 (14%)
Nemours Children's Health System	248 000 (11%)
Seattle Children's Hospital	153 000 (7%)
St. Louis Children's Hospital	379 000 (17%)

Data were extracted from electronic health records during calendar year 2012.

The i2b2 data model and integrated cohort discovery application has been designed to be ‘data-browser friendly’, allowing individuals to explore high level concepts and identify cohorts of interest, but it does not have a library of highly detailed analyses. The OMOP data model and analytic methods applications are more ‘analysis-focused’, with a library of highly complex queries involving numerous variables and relationships between variables. Thus, the two data models, applications, and tools are complementary with i2b2 supporting cohort discovery and patient recruitment and OMOP supporting data analytics for CER.

PEDSnet is implementing a centralized data-coordinating center (DCC) for aggregating specified data elements across institutions. PEDSnet may also support distributed queries when that strategy is more suitable for particular research questions.

To leverage existing institutional investments and capabilities in i2b2 and OMOP, PEDSnet will support data submissions using either i2b2 (figure 1, top pathway) or OMOP (figure 1, bottom pathway). The PEDSnet DCC will develop conversion routines for replicating i2b2 data into OMOP and vice versa. Institutions can provide data in whichever format fits local data efforts. The burden of transforming data into the other data model will be managed centrally at the PEDSnet-CDRN DCC, which is responsible for data management, quality assessment, and network-based data analytics. Consequently, each site will have access to two versions of its data (i2b2 and OMOP format), both of which will conform to national terminology standards.

### Terminology harmonization

Differences in data structures and codes across institutional electronic health records (EHRs) are a significant barrier to multi-institutional data sharing.<sup>18–21</sup> PEDSnet will require institutions to harmonize variables and value sets using terminologies proposed by the US government and health care community (eg, current Department of Health and Human Services (DHHS) Meaningful Use certification criteria, such as SNOMED-CT, ICD, LOINC, RxNorm) and other terminology standards that support data exchange (eg, CDISC ODM and the HL-7 consolidated CDA).<sup>22–24</sup> The National Library of Medicine (NLM), under contract with DHHS, supports the Value Set Authority Center (VSAC), which serves as the national resource for defining all terms that will be required for quality reporting from EHRs.<sup>25</sup> Similarly, the NLM Common Data Element Resource Portal provides a central resource for NIH-sponsored initiatives to support interoperable clinical research.<sup>26</sup>

### Linking to the NIH pediatric terminology effort

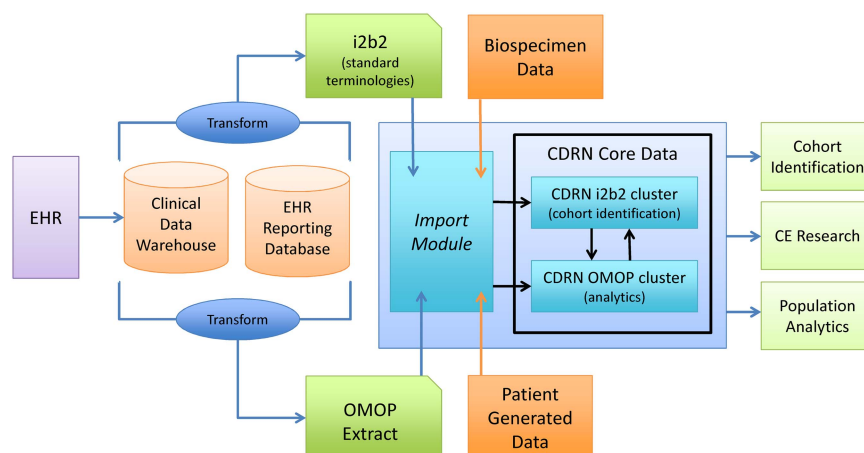
Pediatric concepts are poorly represented in existing terminology standards. The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) supports a pediatrics terminology harmonization effort focused on improving the coverage of critical pediatric research terms in clinical terminologies such as SNOMED-CT.<sup>27</sup> Patient-centered registries often develop highly disease-specific questions, responses, and outcomes. For example, the ICN registry contains disease-specific questions and responses, such as ‘perirectal disease at current exam’ or ‘mildly inflamed skin tag(s), 1–2 indolent fistulas with scant drainage (no tenderness)’, that are required for adequate description of specific conditions. These terms, however, are unlikely to be found in any standard terminology and therefore are more difficult to harmonize with relevant data available from partners outside of ICN. PEDSnet will partner with the NIH Pediatric Terminology effort to submit new

**Table 2** Diversity of clinical data systems at PEDSnet institutions

	Boston	CHOP	CCHMC	Colorado	Nationwide	Nemours	Seattle	St. Louis
EHR system	Cerner for ED, inpatient, ambulatory, pathology, Synapse for PACS	Epic (EHR), Meditech (lab), CardioIMS (cardiology) CompuRecord (anesthesia) EasyViz (RIS)	Epic	Epic	Epic (EHR), Cerner (RIS, Periop, Anesthesia, Picas, Home Health), Sunquest (Lab)	Epic (EHR) Sunquest (Lab)	Cerner	Allscripts Enterprise (outpatient), Sunrise Clinical Manager (inpatient)
Year deployed	1998–2010	1998–2011	2007–2012	2007	2006–2008	2003–2008	2002	Allscripts Enterprise 2005; Allscripts Sunrise 2009

CCHMC, Cincinnati Children's Hospital Medical Center; CHOP, Children's Hospital of Philadelphia; EHR, electronic health record.

**Figure 1** Overall architecture and data flows in PEDSnet, highlighting dual methods (i2b2, OMOP) for data submission and sharing.



pediatric terms and their definitions to national and international standards bodies, such as the NLM and the International Health Terminology Standards Development Organization (IHTSDO; <http://www.ihtsdo.org>), the organization responsible for the development of SNOMED-CT.

The PEDSnet common data models will have breadth (across all 2 million children in NPLHS) and depth (detailed clinical data, patient-reported outcome (PRO) data, and administrative data for the three related disease cohorts). The EHR-derived data will include structured patient demographics, anthropometrics, physiological measurements, diagnoses (mapped to SNOMED-CT), medications (mapped to RxNorm), laboratory results (mapped to LOINC), procedures, and specialty-specific observations (mapped to standard terminologies when terms already exist). PEDSnet will implement an opportunistic terminology mapping approach, starting with most widely used laboratory and physiological measurement concepts across the sites and all clinical concepts relevant to research use cases. Future CER studies may require additional data elements, which will be mapped at that time.

## PATIENT REPORTED OUTCOMES

The digitization of healthcare is transforming the potential for clinical research as millions of patients and encounters become available through electronic records. It is less clear, however, how patients' preferences and perspectives on health, well being, and behavior will be obtained or utilized. Until recently, virtually all PROs were recorded using paper. Today, many electronic data capture systems, including interactive voice response, handhelds, tablets, and other web-enabled technologies, exist but are not used widely in clinical settings. While progress on ePRO systems<sup>28</sup> has been made in fields such as oncology,<sup>29</sup> national consensus on a common set of PROs for EHRs has been elusive.<sup>30-31</sup> Research to date has demonstrated that PRO administration increases chart documentation of scores and associated diagnoses, but thus far PRO data collection has had little impact on patient care and outcomes.

All PEDSnet institutions have some experience using patient-reported data for quality improvement, clinical practice, or research applications, and as a result have been developing capability for obtaining ePROs and other digitized patient-reported data. Across PEDSnet institutions, technology options that currently exist or are planned include:

- **Epic PRO capture:** With its software release in Fall 2012, Epic, a leading EHR developer, provided new capabilities for

patients to complete PRO measures in waiting rooms (on tablets or kiosks) or on their home computers via a patient portal. Surveys can be tied to events, such as an upcoming visit or a scheduled surgery, simplifying the physician's use of ePROs in follow-up (eg, a physician could 'order' a pain PRO 1 week pre-surgery, 1 week post, and 3 months post). Five of the eight PEDSnet-CDRN institutions will have the Epic PRO functionality available by the end of CY2013. The NIH PROMIS (<http://www.nihpromis.org>) measures for adults and children can be accessed using this technology.

- **Research Electronic Data Capture system (REDCap):** REDCap, from Vanderbilt University, can be used to collect self-reported ePROs and other electronic patient-reported data via questionnaires.<sup>32</sup> Boston Children's Hospital has created an interface that converts data from REDCap into i2b2 format that can be used to integrate patient-reported data obtained using REDCap into the PEDSnet CDRN.

These two systems will enable all PEDSnet-CDRN institutions to incorporate ePROs during in-clinic visits or through online recruitment outside the clinic. In preliminary work, we have found that the best approach for collecting high rates of PRO data is to obtain them in the waiting areas before clinic visits, rather than via a pre-visit email.<sup>33</sup> PEDSnet's patient engagement work will include extending patient interactions into alternative media, such as web applications and SMS text messaging, which may be more effective methods for obtaining PROs from a high proportion of participants.

## NATIONAL DATA PARTNERS

PEDSnet has established new relationships with two national companies that manage pharmacy benefits (Express Scripts) and multi-payer administrative databases (IMS Health). Express Scripts is a Fortune 100 company that processes pharmacy claims for 100 million Americans. Data from Express Scripts provides information on medicines actually dispensed to the patient, whereas EHR data provides information on medications prescribed. Knowing which medications are prescribed and dispensed provides valuable information about patients' adherence to medical regimens. A pilot study on inflammatory bowel disease patients seen at St. Louis Children's Hospital found that Express Scripts data could be linked to EHR data for 60% of those patients. IMS Health is one of the world's largest providers of healthcare 'big data'. It integrates data from a variety of sources, such as medical, hospital, and other healthcare records sourced from multiple data suppliers. These databases contain



over 16 billion records of standardized, patient-level, de-identified healthcare encounter records representing all 50 states and more than 260 million patients worldwide. Data are linked at the patient-level across data sources. One of the great strengths of the IMS Health database is that it is multi-payer and national in scope—that is, includes many health insurers within and across markets. Adding insurance claims to EHR data will provide insights on use of services outside the children's hospitals, including use of outside specialists and emergency departments.

## CONCLUSION

PEDSnet will transform pediatric healthcare and children's health by developing an extensible and efficient digital infrastructure that enables all participants to collaborate in the work of producing new knowledge and improving health and care delivery. PEDSnet benefits from robust pre-existing resources and a unique history of collaboration by children's hospitals that has fundamentally reshaped outcomes for previously fatal diseases, such as cystic fibrosis and many childhood cancers. By developing a dual common data model platform with i2b2 and OMOP, PEDSnet allows organizations to participate in the data-sharing network based on existing institutional priorities and programs. By contributing to pediatric terminology standards activities, PEDSnet will help expand the availability and interoperability of complex pediatric concepts that are not present in existing terminologies. As the underlying digital infrastructure to a LHS, PEDSnet will enable the rapid implementation of new evidence into clinical practice and will address fundamental questions of clinical effectiveness for children and their families, particularly for individuals affected by serious, and generally rare, illness that persists into adulthood.

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